

# Original Research

## Communication about sexual problems and sexual concerns in ovarian cancer: a qualitative study

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The assumption that ovarian cancer and its treatment—hysterectomy, oophorectomy, and chemotherapy—have considerable psychosexual effects is reasonable. Studies in other gynecologic cancers show that sexual activity is affected and that communication about this topic is poor.<sup>1-4</sup> These issues have been neglected in ovarian cancer, so in this qualitative study we explored its psychosexual effects and the level of communication between women and health care professionals about sexual issues.

### PARTICIPANTS, METHODS, AND RESULT

Detailed interviews were conducted with 15 women who had ovarian cancer (median age, 56 years [range, 42-71]; median time since diagnosis, 18 months [range, 8-120]) and who were identified from a sampling survey as sexually active or as inactive for reasons related to the condition. Topics included prediagnostic and current sexual behavior and response, satisfaction with sex life, and importance of sex. Interviews were audiotaped, transcribed verbatim, and analyzed using grounded theory methods, starting after the first interview.<sup>5</sup> Each of us read the transcript, noting themes and issues, and concepts pertaining to similar issues were grouped into categories. As more interviews were conducted, a thematic framework of the categories and their associated themes was produced, and this was systematically applied to each transcript as we searched for evidence of the categories and themes. Semi-structured interviews were conducted with the women and 43 clinicians and nurses in Leeds to determine their attitudes about, and experiences of, written or verbal communication about sex. The local research ethics committee granted approval for this study.

The condition affected women's sexual desire and raised fears about sexual activity (for example, fear of recurrence) and relationship concerns (for example, fear of rejection). The couple's ability to discuss sex and the woman's perception that sex maintained normality or control contributed to whether or not sexual activity was resumed. The experience of physical problems (for example, dyspareunia or vaginal dryness) or psychological distress affected the continuation of sex, and the frequency of sexual activity was often reduced. Over time, physical problems reduced in severity, but the psychological distress persisted. For some women, sex never occurred again, and the effects on their self-esteem and relationship were devastating. Loss of fertility also caused distress.

### Summary points

- Previous studies have shown that gynecologic cancers affect sexual activity
- Women with ovarian cancer in this study wanted medical staff to discuss sexual issues
- Health professionals rarely discuss sexual issues because of lack of time, embarrassment, or inexperience
- Professionals need training to help them communicate more comfortably with their patients about sexual issues

Most women thought that a health care professional should have provided written information or discussed sexual issues with them. No patient received written information, and only two received brief verbal information—a medical oncologist told one woman that the hospital had creams to help if intercourse proved difficult, and another woman vaguely recalled a surgeon saying something, but she still felt unsure about the safety of sexual activity.

The Table shows women's attitudes toward communication about sexual issues compared with the reality that they faced. Some women felt uncomfortable discussing sex, but they felt that the benefits would outweigh any embarrassment. Women felt that time available to discuss psychosexual concerns was limited, but they did not seek extensive information—reassurance of the safety of sex, reassurance that their problems were not unique, and permission to discuss concerns were often all that was needed.

The Table also shows the attitudes and behaviors of health care professionals. All but one thought that medical staff should discuss psychosexual issues; however, only four clinicians (25%) and five nurses (19%) did so. Knowledge about the effects of ovarian cancer on sexual functioning was lacking, with few health care professionals being aware of the problems that can occur.

### DISCUSSION

Ovarian cancer affects sexual functioning, but health care professionals' knowledge about this is inadequate, as is their communication with patients about sexual issues. A larger prospective study starting from the time of diagnosis

Belief and reality regarding communication about sexual issues and concerns in patients with ovarian cancer

Patients' beliefs	Health care professionals' beliefs
<b>Yes, medical staff should have talked to me about sexual issues</b>	<b>Yes, we should discuss sexual issues with patients</b>
"It would help you understand that it is normal to feel like I did after the chemo and the operation"	"Which sexual problems may occur"
"I could have understood why I was having sexual problems if they'd have said you might have problems sexually because we've removed this or that"	"Why sexual problems may occur"
"It would have provided reassurance—a light at the end of the tunnel"	"Reassurance that sexual activity will not cause a recurrence"
"You should know what's going to happen instead of it hitting you like a ton of bricks"	"Reassurance that sexual problems are normal"
	"Advice or help is available"
<b>Patients' reality</b>	<b>Health care professionals' reality</b>
<b>No, medical staff didn't talk to me about sexual issues</b>	<b>No, we don't often discuss sexual issues with patients</b>
"I didn't know much about how sex would be affected; I just had to go through and find out for myself"	"It's not my responsibility"
"You have no idea about how the cancer will affect you sexually"	"Talking about sexual issues is embarrassing"
"Nobody talks about sex, and you wonder whether it is right that you feel different"	"I'm not sure what types of sexual problems patients experience"
"The doctor said that if I was having problems with sex, the hospital had creams to help me, but nothing else was said"	"I don't feel confident talking to patients about sexual issues"
	"There's no time to discuss sexual issues"
	"I wait until a patient asks about sex"

is planned to identify the prevalence, duration, and severity of sexual problems in patients who have ovarian cancer.

Health care professionals need training to help them communicate more comfortably about sexual issues. Detailed discussion may be unnecessary—just a few reassuring words may be enough to relieve some of the fears and problems provoked by ovarian cancer and its treatment.

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